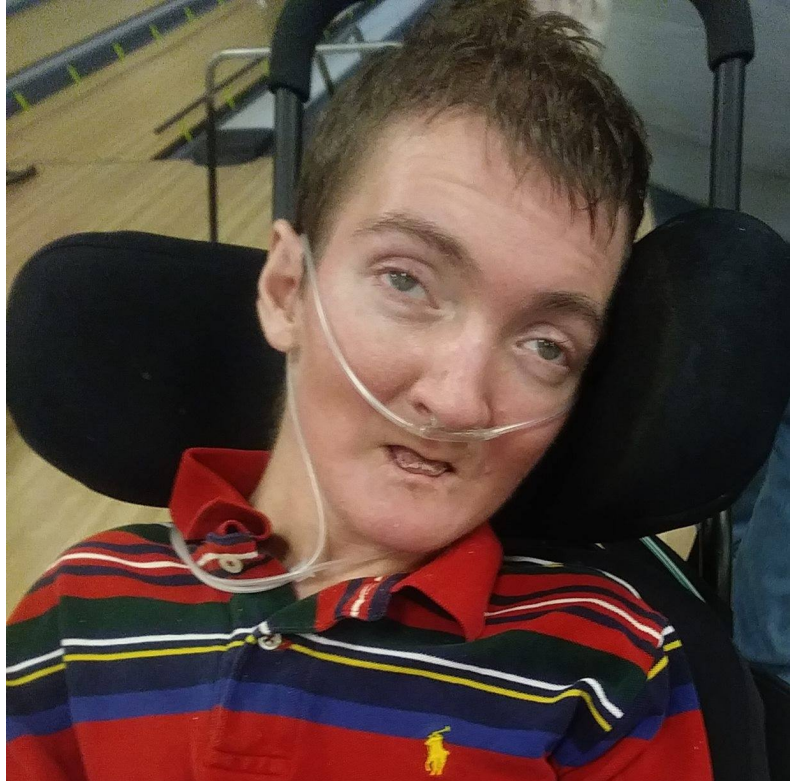


Medically Complex Children & Adult Services: A Complex Dilemma

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The HCBS Waiver ensures:

“Settings are integrated in and support full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources and receive services in the community, to the same degree of access as individuals not receiving Medicaid services”

“Ensures an individual’s...dignity and respect”

“Optimizes...independence in making life choices”

“Facilitates individual choice regarding services and supports and who provides them”

From DSPD:

The scope of nursing tasks requires professional judgement under the circumstances, so no clearly defined list of nursing tasks exists. The Aging

Waiver developed a list of commonly encountered tasks generally accepted as “skilled nursing,” for reference:

- Parenteral lines/enteral tube feeding
- Wound care/dressing changes
- Toileting
 - Catheters/ostomy/stoma/rectal tubing care
 - Assisting with enemas and/or suppositories
 - Assist with bladder and bowel needs or problems for persons with a known infection risk
- Tracheostomy care
- Suctioning
- Care related to IV's and PICC lines
- Care related to any equipment or supplies such as ventilators and oxygen equipment
- Oral feeding for participants at risk of aspiration
- Medical skin care



Currently, individuals who require “skilled nursing services” are limited-**and in many cases, prohibited-** from having choices of where and how they receive services.

In order to comply with the HCBS Waiver, the state of Utah must demonstrate that *all* individuals have access to home and community based services, regardless of their ability: ***medical needs are not an excuse to limit services***

Is this really necessary?

- In the last **3 years**, Primary Children’s Hospital has placed **629 g-tubes** and **360 trachs**
- **Medicine is advancing-these numbers will increase as more individuals reach adulthood**
- Once they turn 18, the current waiver options exclude them from receiving the same opportunities for services outside of the home, *simply because of their nursing needs*

With your support, we hope to work together with DSPD, DOH, CMS and providers to find a solution to give more individuals options for care

Imagine being
invited to a party,
but with
restrictions:



**Confused by this invitation? Maybe
it's because you didn't know this:**

Every day in Utah, children & adults who have a feeding tube & receive DSPD funding are limited in their choice of providers & who can feed them.

Per the DOH, ONLY nurses, parents, family and friends can handle a feeding tube-not unlicensed staff-even if a RN has trained & passed them off! Even foster parents (called professional parents) with specialty training aren't allowed! Caregivers are expected to leave their jobs to come & manage feeding tubes or pay out of pocket for a RN. If DSPD-funded day support providers want to hire a RN, it is at their own expense-they can't use DSPD funds to pay a RN.

**It's like being invited to a party, but
unless you follow these
discriminatory rules, you can't eat!!**

Insurance companies don't pay for a RN to come for every feeding-nurses teach & trust others to do it in the home, school & community. Why is a DSPD-funded setting any different?

As Utah analyzes HCBS compliance, it is critical to remember that ***some of us still don't have the right to eat!***

Help us get the right to be fed *anywhere*, by *anyone* who has been trained,
regardless of the source of funding!

tubefeedme.blogspot.com

